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The Experiences of Mothers Living with Autistic Children: A Qualitative Descriptive Phenomenological Approach

Than Than Win[1]* and Htwe Htwe Nyunt[2]

Abstract

This study adopts a qualitative descriptive phenomenological approach to explore, analyze and document the experiences of mothers raising and living with autistic children. In doing so, the study recruited seven mothers of autistic children in Myanmar using a non-probability, purposive sampling method. Data was obtained through in-depth interviews and focus group discussion, and it was analyzed using Giorgi's method. Six major themes emerged: loss of parental hopes and childhood significances, initial recognition and diagnosis, misunderstanding and assumptions about autism, mixtures of emotions experienced by the mothers, challenges in nurturing autistic children, and the mothers' expectations about the future of their children. Raising and caring for an autistic child was challenging for the mothers as their children required constant care round the clock and for the entire span of their lives. Therefore, a comprehensive training in nursing is vital for these mothers. The findings of the study contribute to the literature on autism and forms as a basis for future research on this topic, especially on how living with an autistic child can have an effect on their siblings and other caregivers of autistic children using different approaches.

Keywords

Challenges; experiences; mothers; autistic children; caregivers

Introduction

In a global population of over seven billion people, 26% are of the ages between 0-14 years. Of this group, 5.1% have childhood disabilities which are sometimes referred to as early childhood developmental disorders (WHO & UNICEF, 2013). Early childhood (infancy to that of eight years old) represents a very crucial stage of growth and development for every child (WHO, 2007), and in this stage certain developmental issues can arise. Autism is the most common of the early childhood developmental disorders, and the most common of five major disorders according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (American Psychiatric Association, 2000). Autism is a childhood developmental disorder that is characterized by a combination of qualitative impairments in social interaction, communication, and restricted, repetitive, and stereotypical patterns of behaviors, interests, and activities (American Psychiatric Association, 2000). Over the past 15 years the number of people diagnosed with autism from noticeable behavioral traits has increased (Barbera, 2007, p. 287). According to the Centre for Disease Control and Prevention (2012) the global estimate of those who have ASD was one in 150 in the year 2000, but that number increased

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[1] Maternal and Child Health Nursing Department, University of Nursing, Yangon, Myanmar
[2] Adult Health Nursing Department, University of Nursing, Yangon, Myanmar
*Than Than Win, corresponding author. Email: thanthanwin.uon@gmail.com

dramatically in 2010 to that of 1 in 68 (ADDM Network, 2012, p.19) and 35% of ASD cases were classified as autism (Giarelli, 2013, p. 6). Thus, the prevalence of these cases and the ensuing care can be taxing in its emotional and economic onus for families as well as a difficulty to grapple with for entire countries (WHO, 2013, p. 2).

Moreover, autism is a diagnosis that, when given to one person, can change the lives of that individual's family. This is due largely to the amount of care associated with this life-long and non-curable condition (Barbera, 2007, p. 288). As its cause is still unknown, and autistic children are content to live insular lives that are disconnected to others, autism is an onerous challenge for families and also a significant problem for health care providers. It is believed that parents of children with autistic disorders, and especially mothers, face a unique set of challenges that affect their lives. Therefore, programs that assist in issues devoted to autism should be focused not only on the child but also on the family, and chiefly in assisting mothers. Emotional support and physical health care are extremely important aspects in overall management of ASD conditions (Myers, Johnson & Council on children with disabilities, 2007, p. 1174).

Although accurate statistical information on autism in Myanmar is not available, there are some rough estimates. Records conclusively state the existence of 350 autistic children, and more generally, that there are around 700,000 children who experience one form or another of ASD in Myanmar. This is extrapolated from records kept in private special education schools for autism in the Yangon metropolitan area, (Myanmar Autism Association, 2013). Although there have been many international studies on autism, very few studies have been conducted in Myanmar. Therefore, research done in this country for the purpose of uncovering the feelings and life experiences of these families was needed. Much of the information gained in the study was garnered from the School for Disabled Children, Kyaik Waing, in Yangon using the qualitative descriptive phenomenological approach. Specifically, the information came about chiefly through extensive interviews with seven mothers of autistic children who were attending this school; and it is believed that the information is of particular importance for health care providers who need to understand the feelings and life experiences of mothers with autistic children, and, of course, apply this understanding to improve the lives of autistic children and the support of their families, as well as for promoting public awareness.

Research Question

For this study, the main research question was what the life experiences of mothers of autistic children in this country were actually like. Therefore, interview guided questions were deliberately written to be open-ended, and unstructured to reveal the life experiences of mothers with autistic children.

Purpose

The purpose was to uncover the life experiences of mothers with autistic children who were attending the School for Disabled Children, Kyaik Waing, in Yangon, Myanmar. The ultimate objective of the research was to achieve a deeper understanding of the feelings and experiences of these mothers.

Methodology

Study design

In this study, a qualitative descriptive phenomenological approach was used with qualitative research methods, and it became a means from which to study these individuals and discover hidden aspects of their lives. And all understanding was for the practical aim of allowing the nursing practice to have better empathy of the plight of mothers of autistic children (Polit & Beck, 2012).

Study participants, sampling method, setting and period

Seven mothers of autistic children who were attending the School for Disabled Children in Yangon were purposively selected using the non-probability, purposive sampling method and based upon their ability to provide rich, detailed description of their experiences as mothers with autistic children. Qualitative data from the mothers was collected in convenient and familiar places for them such as at their homes or at the school. This study was conducted from May of 2014 to October of 2015.

Data collection method and procedure

In this study, face to face in-depth interviews were done using unstructured, open-ended questions, focused group discussion (FGD), and audio recordings for data collection. Observation of gestures, facial expressions, appearance, and body language was also noted during the interviews. Notes were written with respect to such things as the emotional content, and tone of voice. After establishing rapport with the participants, individual in-depth interviews were conducted at the participant's home or convenient places for them where they felt at ease to express their experiences and feelings. The interview schedules were arranged with participants in a manner that would best facilitate their convenience and each interview usually lasted for around one hour, but always subject to the participants' ability to express their feelings. The researcher, utilizing a more flexible, open-ended conversational style and probing questions did so appropriately for each individual based on the expressions of each of the participants. All interviews were documented with an audio recorder. Participants were interviewed around four times to ensure adequate understanding.

After interviews were conducted with each of the mothers, a focus group discussion was held to achieve more qualified data. Five out of the seven mothers who participated in this study contributed to the group discussions held at the office of the School for Disabled Children. All five mothers collectively discussed and shared their life experiences actively in an uninhibited frankness. The information gained in the focus group discussion, which used data triangulation, was essentially for the purpose of reaffirming the accuracy of the earlier findings. By conducting FGD with the same participants of the one-on-one interviews, the mothers participating in the group session realized that all feelings which they were experiencing had some similarity to the other women in the group and that they were probably endemic to all women who have a child who is autistic. This mitigated the sense of isolation or being alone in addressing these issues. As most of the mothers were even more at ease in discussing their situations openly in this forum, the FGD session complemented the one-on-one interviews.

Data Analysis Method

For this study the Giorgi (2009) method of data analysis was used. The method is based on Husserl's descriptive phenomenological philosophy, and acts as an alternative to the epistemology for human science research. Giorgi's (2009) method involves five steps and these steps are to utilize a phenomenological emphasis, to read the entire written account for a sense of the whole, to delineate unit meanings, to transform the unit meanings into psychologically sensitive statements of existential meanings, and to synthesize a general psychological structure of the experience based on the constituents of the experience.

Ethical Considerations

For this study, research and ethical approval was obtained from the Research and Ethical Committee at the University of Nursing, in Yangon, Myanmar. The Research and Ethical Committee's approval number is 5/2014 and the date of the approval was May 21, 2014. Permission from the Principal of the School for Disabled Children was also obtained. The researcher got informed consent which covered all the necessary precautions regarding enrollment, confidentiality of data collection, data management, and data analysis from each participant after detailed explanation about the study. The mothers who contributed to the study were also informed of their rights as participants which included the right to withdraw from the study. Pseudonyms were used to achieve anonymity and to protect confidentiality of the participants. Agreement from all participants, those responsible for the study, and members of the committee was obtained prior to publishing the results of the study.

Emerging Themes

To merge the personal feelings and experiences of mothers with autistic children into specific objective themes, five steps of analysis were carried out in as meticulous and consistent manner as possible.

Step (1) To use a phenomenological emphasis

The phenomenological approach of bracketing anecdotal information into objective data was done. To achieve full empathy with these mothers with autistic children, the researcher set aside her own presuppositions, whether theoretical, cultural, or experiential in nature.

Step (2) To read the entire written account for a sense of the whole

All audio interviews were transcribed verbatim with the accounts of participants' facial expressions, body language, and tone of voice. Then, they were read and reviewed assiduously to obtain a sense of the whole and to grasp common sense descriptions of participants' everyday realities living with autistic children and were done without critical assessments.

Step (3) To delineate meaning units

The narratives of the texts were scrutinized to produce unit meanings after frequent readings. For markings on unit meanings, the numerical identification color coding was done. Additionally, these unit meanings were copied out in separate sheets in order to have clear analysis.

Step (4) To transform the unit meanings into psychologically sensitive statements of existential meanings

Then, the unit meanings were transformed into descriptive and psychologically sensitive expressions in the third person without changing the content of the meaning expressed by the participants.

Step (5) To synthesize a general psychological structure of the experience based on the constituents of the experience

Shared meanings of the participants' experiences were sought, and those that were relevant to general psychological consistencies became material that was recorded for the study.

In all, this became six major themes that described and detailed the life experiences of mothers with autistic children.

1. Loss of parental hopes and childhood significance of autistic child

Every parent has high aspiration for their children. Before these mothers were told that their children were diagnosed with autism, they also had hopes for their future success. After these diagnoses, those dreams vanished. The mothers in this study explained the hopes that they had for their children during their respective pregnancies, and after the deliveries.

a) Vanished expectations

Each participant felt very excited and in high spirits at the time of the pregnancy. However, those hopes and dreams vanished after the diagnosis. Each mother expressed those feelings in similar ways. One mother said, *"I felt very exultant when I became pregnant when over [the age of] thirty. It had been my goal to raise my child to be highly intelligent and outstanding. But all of my dreams have been destroyed."* Another mother said, *"I had great expectations for my child. I wanted my child to be a successful businessman with a high intelligence. Ah…you know, it has already gone wrong now."*

b) Significant events during antepartum, intrapartum and postpartum periods

All participants reported that they experienced some problems during their respective pregnancies, labor, and immediately after the births of their children. They faced situations such as early labor, mild to moderate preeclampsia, post-term deliveries, prolonged delivery time, and complications related to the newborns. One mother said, *"I suffered from increased blood pressure during my pregnancy due to preeclampsia."* Another mother stated, *"My OG helped me to deliver my child with vacuum extraction during the delivery because of delayed progress and post term labor."* A third mother stated, *"Although my doctor planed my delivery by induction, I* *underwent urgent operative delivery due to prolonged labor. They also told me [at that time that] the baby was suffocating with amniotic fluid."*

c) Childhood illness and injury of autistic child

It should be noted that five of the seven autistic children of these mothers suffered from high fever, fits, and severe illnesses with diarrhea, and had a history of frequent minor head injuries from falls.

One mother said that her child *"had a high fever with fits when he was fourteen months old."* A second mother said that her son *"often got head injuries, hitting the floor, slipping from my hands, because I couldn't handle him in my first experience of nurturing a baby. When he got older, he fell on his head frequently when jumping down."* A third mother said, *"My son got a high fever of 106 F, and was seriously ill at nine months of age. He nearly lost consciousness. We thought for sure we would lose him."*

2. *Initial recognition and diagnosis*

a) Initial recognition of delayed development and unusual behavior, and age of diagnosis

All participants reported that they noticed delayed development, unusual behavior, and strange play-habits prior to their children being diagnosed with autism. The children's ages upon getting these diagnoses ranged from two to six years old and most were of the age of three. One mother stated, *"He didn't play with other children and couldn't speak a full sentence. Staying apart from other children, he usually played alone. Sometimes, he used to laugh for no reasons and ran here and there in the house without feeling tired. Also, he usually said one word or phrase repeatedly. The specialist diagnosed him with autism when he was three."* A second mother stated that *"The big unusual thing was that he hit his cheeks, gradually at first, and then he did [it] severely. He seemed to lose his mind [furthermore], he became violent toward other children. He usually plays by placing toys in a row or in line and shouts in a strident tone when something is wrong. Being restless, he never sits still and walks back and forth in the room. He can't bear loud music and sounds from a blender. If he hears these sounds, he hits his cheeks close to his ears. His age was five years and eleven months when he was diagnosed with autism."* A third mother said that her son had *"a habit of jumping from high [places] and it was noticed that he had poor eye contact. I found he had a poor attention span and [only] looked at us when we called him. After visiting a child specialist, he was diagnosed with autism at the age of five."*

b) Immediate response to diagnosis

Each of the participants recalled that immediate response to the diagnosis of "autism" with emotions of anxiety, fear, denial, acute grief, and uncertainty. One mother stated, *"At the time of the diagnosis, we didn't know what autism was. A specialist counseled me not to expect too much from her in the future. We felt [a sense of] panic… and I started to weep uncontrollably. [Even now] I shed tears for my daughter many times whenever I see her. I can't find the reason why this has happened in our lives and I feel great pity for my child. My husband's parents were vociferous in their denials that their grandchild should be autistic."* A second mother said, *"I had never heard about autism so I felt anxious about my child. I was in doubt as to whether my son would be able to speak for a long time, and [I wondered] if he could [ever] fit in society."* A third mother said, *"When I saw my son beating his cheeks with his hand as if he had lost his mind, I was shocked. I was shocked [even further] when I visited a doctor with my son. At this time… this time [suddenly crying with a flushed face] we came to know this [she seemed hesitant to use the term "autism"]. As I knew the lifelong consequences of autism, I felt nervous and didn't know what we should do. I was shedding tears all night."*

c) Later response to diagnosis

These mothers' anguish at the result of hearing these respective diagnoses continues even to the present day. One mother said, *"I reduced my expectation for him. I was determined to care for him as much as I could."* A second mother said, *"I am filled with grief for my child whenever I think about her. Tears roll down on my cheeks whenever I look at her. Still, I've made up my mind that I will do my best for her. If I really love her, I won't be disappointed."* A third mother said, *"Even though he [has a diagnosis of] autism, he is a human being. I have become reconciled to this fate by seeking consolation in [a belief] that this is God's will. For better or for worse, he is part of my life… [her voice fades to a whisper], so I will do my best."*

3. Misunderstanding and assumptions about autism

a) Misunderstanding about delayed development and unusual behaviors

Prior to these diagnoses, all participants assumed that the delayed developments of their respective children, which they had observed, was normal as they assumed that cognitive development for boys takes place later than that of most girls. Some of the participants thought their respective children were deaf. Prior to the diagnoses all participants had misinterpreted the anomalous behavior of their autistic children as "bizarre" or "bad" behavior. One mother, speaking about information her own mother conveyed to her, said, *"She believed children can be naughty for longer than the first year. So, we all assumed it was just normal. Even when he started hitting his head against the wall, I just thought that my child was highly strung."* Another mother said, *"Before I knew she was autistic, I supposed she behaved badly because she didn't want to obey us. As I got tired and angry with her unusual behaviors, I even beat her sometimes. My neighbors also commented that she was a mischievous girl."* A third mother said, *"Due to his lack of eye contact, I assumed that he wanted to stay alone, and did not realize that it was the result of a disease. We also inferred he might be deaf or have a poor sense of hearing when he never looked at us when we called on him."*

b) Mothers' beliefs regarding the causes of autism

After confirmation of these diagnoses, five of the mothers felt that the cause of autism might be related to advanced age and other physical deficiencies, past use of contraceptives, and having suffered depression during pregnancy. One mother said, *"It may be due to the long period between my pregnancies. I regret this having happened. He would not be autistic if I had planned to get pregnant when I was under thirty."* A second mother claimed that one prevalent belief in her community was that *"A child can become autistic if the mother gives birth in old age."* A third mother said, *"I felt very guilty [for his condition of autism]. I became pregnant immediately after stopping the use of birth control. Actually, I should have discussed this situation with my doctors. Moreover, I used oral contraceptives for seven years during my marriage. I think that's the reason [for his condition]."*

c) Cultural beliefs

The study found that cultural beliefs and practices play a significant role for mothers in obtaining a more sanguine acceptance of their life situations. All these mothers believed autistic children come from a "treasure trove." In Burmese culture, a treasure trove is a holy place in which gems and gold belonging to a holy person can be transferred as a blessing to living recipients. Some of these mothers believed that bad deeds from a child's past life made him or her autistic. One mother said, *"We believe our child is someone who comes from a treasure trove. However, [it might also be that] he committed bad deeds in his past life so we have donated some money and material to pagodas to atone for his bad deeds."* A second mother said, *"We… believe our* *child is someone who came from a treasure trove and that he can't speak because spirits do not allow him to speak as a promise in the past life."* A third mother said, *"From the teachings of the Lord Buddha, it can be argued that he is autistic because of his misdeeds in the past life. I often offer donations to the monks at a monastery. Every act of merit that we do for him will ensure that he does not become autistic again in the next existence."*

4. *Emotions of the mother of the autistic child*

The mothers of the autistic children in this study experienced a range of emotions on a daily basis such as feeling annoyed and angry, anxious, and tense. They also suffered from depression.

One mother said, *"I feel anxious for his future now, more than ever. From the point in which I send him to school on the school bus, to when he comes back, I'm always afraid that he might get lost on the road, or that he might fight with other children. I can't express [my feelings] in words. It is more than I can say."* A second mother said, *"The days in which he became violent to family members at home has caused me to experience a lot of stress [even now]. It causes me to have increased blood pressure and headaches. It disturbs me all the time, and I don't have any desire to eat or sleep. It is too much."*

A third mother said, *"After so many years, I realize now that my son can't learn effectively at school, [or function well] in society and in the world [she sheds tears which roll down on cheeks as she speaks]. Now, I feel sad whenever I join other friends whose children are normal. Sometimes, I cut myself off from my friends, and even [don't take] phone calls."*

5. *Challenges of mother in nurturing the autistic child*

Based on conversations with the participants, it was apparent that they went through many daily challenges in nurturing and raising their autistic children.

a) Physical impacts

Many of the participants reported that their children were totally dependent on them for daily activities and because of this they were in a state of physical exhaustion.

One mother said, *"I'm not able to get a sound sleep because of my worries about him. My body and mind [feel numb] as it's very rare to rest comfortably with him [around]. So I feel exhausted day and night."* Another mother said, *"I have to help him in every single activity. Even in activities that he knows how to do he shouts at us, demanding that we do them for him. I need to do everything at home for him like his personal assistant."*

b) Psychologically impacts

The five participants stated that their biggest fear was of becoming pregnant again. The first mother said, *"The main concern I have in ever becoming pregnant again is that my second child might become autistic like my first child."* A second mother said, *"I'm holding a time-bomb, wondering when it'll explode. [He has very] erratic behavior and rapid mood swings. I am always concerned about what will happen to my child, and I'm [always] in a state of panic whenever I hear a loud crash or noise."* A third mother said, *"I sometimes feel unlucky in my life. I feel as though I have become like a prisoner [in house arrest], always having to take care of him. I have raised him but there are continual problems that arise from caring for him, so my life is filled with problems from dawn to dusk. I have to give him all of my time, my energy, and finally my life."*

c) *Socioeconomic impacts*

These mothers spoke of being so encumbered that they were not able to participate in social activities or maintain jobs. Adverse economic impacts on their lives not only came from an inability to work, but the high costs of paying for special education and training, and the costs of replacing household items broken or damaged by the mercurial temperaments of an autistic child in the home. Furthermore, conjugal disputes often arose because of the complexities involved in raising an autistic child. The first mother said, *"My husband told me that [the reason our son] can't speak properly was due to my carelessness and failure to teach him. Also, I have minor problems when I go out or attend a ceremony with him."* A second mother said, *"My boy, as he is autistic, does not know table manners. He does what he wants without thinking about whether or not it is proper. So I cannot concentrate on guests or the purpose of social occasions when I go out with him. That's why my life is so insular and isolated without a social life."* A third mother said that *"Even on my son's birthday, the family stays at home, holding the party and slicing the cake [here]. No one is invited because our son can't communicate well."* A fourth mother said that *"[It costs over} one million kyats each month for {my daughter's] expenses. Indeed, her expenses are probably three times more each month than what they would be if she were a normal child."* A fifth mother said that her son *"behaves badly by throwing things at the TV when he loses his temper and his wishes aren't fulfilled. He often destroys furniture and valuable things at home, and his education fees cost a lot every month [as well]."*

6. *Mother's expectations for the future of the autistic child*

Despite having high expectations for the child prior to the diagnosis, each mother was compelled by circumstances to set realistic goals. One mother said, *"I will be satisfied with my child if she can perform basic daily tasks and can look after her belongings properly."* A second mother said, *"At best, I just hope that he is capable of making a living for himself by doing simple tasks such as those in agriculture or animal husbandry."*

Discussion and Recommendations

Discussion

In recent decades, ASD has become a popular topic amongst those teachers specializing in education for special needs students because of its increased prevalence-rate globally. Raising and living with an autistic child is filled with unique challenges that often require conducive environments for optimal outcomes (Bright Tots, 2015b); and eased only marginally by public commiseration which the study has found to be rife in society at large for the life experiences of mothers with autistic children. The participants in this study ranged from 32 to 46 years old. Most were over 30 at the time of their pregnancies, except three who were between 20 and 30. Advanced maternal age is a high-risk factor for delivery of an autistic child. Every ten-year increase in maternal age substantially increases the risk of autism for the child (Croen, Najjar, Fireman & Grether, 2007). Therefore, it might be advisable for married couples to go for counseling in family planning and that they should follow the advice of family planning clinics to circumvent, if not completely curtail, the risk of delivering an autistic child.

Of the seven children of the participants, six were males whose ages were 11, 9, 7, 7, 9 and 11 years old respectively, and only one of the children was a 10-year-old female. This study found that the number of males with autism was substantially greater than that of females in the school, which concurs with other studies on this subject (ADDM Network, 2012). Similarly, the study of Leerkes and Burney (2007) showed that the dreams of each group of parents were upended. After learning these diagnoses of 'autism' the mothers tended to feel hopeless because their dreams were completely ruined. Although individuals experiencing autism have many difficulties in social communications, they sometimes exhibit talents in art, science, and mathematics, and have a flair for memorizing information (Fleishmann, 2005). Nurses can provide emotional support for the mothers, imparting the strengths of their autistic children and encouraging them to foster the particular abilities and skills that each of their autistic children possess.

Although the exact cause of autism is still unknown (Guttovz, 2008, p.30), five out of seven participants thought that their actions and behavior before and during pregnancy adversely affected their children to create the autistic conditions. They assumed that prolonged use of contraceptives, being pregnant at advanced ages, and feeling depressed during pregnancy caused their children to be autistic.

As for contraceptives, oral contraceptive use is not a cause of autism although it is true that statistically women with autistic children did have a higher prior usage of oral contraceptives. As it cannot be proven categorically that taking birth control pills poses any imminent danger to a fetus, the true causes might well be genetic, or environmental (Strifert, 2014). This notwithstanding, every parent should consult health care providers for advice in using appropriate contraceptives.

Studies reveal that mothers feel a lot of anxiety about the behavioral traits that tend to be associated with autism such as poor attention, speech impairments, and improper social interaction (Bright Tots, 2015a). All of the participants in this study were very conscious of these signs in their children. The typical characteristics of autism such as self-injuries, aggression, sensory impairment, and abnormal pain tolerance are often apparent within the first few years of a child's life (Guttovz, 2008, p.30). Similarly, the six children in this study exhibited self-injuring behavior, and behavior which injured other children.

Mothers should monitor their children's development carefully to detect any abnormal or delayed development as early as possible since, when these symptoms materialize in autistic children, they can be reduced substantially through early diagnosis and treatment (Guttovz, 2008, p. 32). If delayed development or unusual behavior is found, a pediatrician or child specialist should be consulted without hesitation so as to gain specific treatment and management for the child. As stated earlier, before receiving these diagnoses, participants had thought of their children as disobedient and insolent. In that sense, it is similar to mothers of deaf children who also reported similar reactions and a tendency, when ignorant of the true conditions of their respective children, to punish them for this "bad" behavior. (Aye-Nandar-Han, 2011). In another study, mothers of autistic children had assumed, prior to the respective diagnoses of their children, that they were mute or deaf or suffering from mental illnesses (Yan-Htoo-Aung, 2014).

Although cultural beliefs and practices helped many of these mothers to psychologically cope with such challenging domestic difficulties, these approaches were for the most part counterproductive for they were actually barriers to achieving accurate diagnoses and providing appropriate management techniques. The initial reaction that each of these mothers usually had upon hearing the diagnosis of a son or daughter was confusion in not knowing what autism consisted of. After learning the nature of autism, there was a sense of distress and confusion caused by the word, which was still relatively unfamiliar to them. Swanepoel (2003) also states that the early response of each mother at diagnosis was grief after acknowledging that the son or daughter would never be a normal child. Similarly, mothers who care for deaf children also reported feelings of shock, guilt, grief, and depression in the diagnostic stage

(Aye-Nandar-Han, 2011). Participants in this study revealed many kinds of emotions associated with having autistic children such as annoyance, anger, anxiety, stress, and even depression. In that respect, the findings of this study are consistent with other studies on this issue. Feelings of frustration and anxiety, pessimistic thoughts, and mental disorders such as chronic depression and anxiety disorders are not uncommon for mothers of autistic children (Blackledge & Hayes, 2006; Yirmiya & Shaked, 2005). Mothers of children with ASD could not fully enjoy social activities, and under enormous stress, tended to not take care of themselves as well as they should both physically and mentally, and this was true at higher rates than mothers of children with other types of disabilities (Mugno, Ruta, D'Arrigo & Mazzone, 2007). In this study, all participants claimed that raising and nurturing autistic children was particularly challenging for mothers because of the physical burdens on them in terms of caring for the daily needs, education, and training of their children. Moreover, their lives were also greatly affected psychologically as well as socioeconomically by having autistic children. A sense of feeling isolated was particularly acute amongst these mothers as they were not able to participate in social activities because most of their time was devoted to the care of their autistic children, and they believed that taking them to religious ceremonies and other formal functions would be deemed inappropriate due to the antisocial behavior that are common traits of autism.

Despite understanding the importance of social engagement as a significant factor in dealing with stress, mothers of autistic children tend to be too busy to find time for going out with friends (Altiere & von Kluge, 2009). Similarly, in this study, mothers reported a sense of isolation due, in part, to not having time to cultivate relationships, but also because of feelings of inferiority to mothers of normal children. Bawi (2012) stated that reduced participation in social activities causes further isolation and discrimination for families with disabilities. Additionally, the author expounds that mothers are often forced to stop their jobs, and professions since they have to care for the autistic child at all times (Bawi, 2012). In this study, mothers of children with autism reported loss of job opportunities as well as loss of income from their own businesses. All of these factors aggravated isolation, and not being able to work aggravated the problems of not having enough money to cover the costs of educating an autistic child, and the costs arising from damage to furniture and valuables the result of the autistic child (Aye-Nandar-Han, 2011; Lwe-Say-Paw-Hla, 2005).

The mothers in this study were grateful that the government established the School for Disabled Children and were pleased with the activities provided there for autistic individuals as well as the implementation of legislation assisting those with disabilities. In recent years, provisions and services for autistic children have been significantly improved. All participants in this study reported that they wanted the government to establish more institutions and schools for disabled children throughout the various parts of the country, and with some programs devoted toward integrating autistic children into mainstream public schools. In 2003, Myanmar implemented the National Action Plan (EFA NAP) which is pursuant to the initiative for the reinforcement of Inclusive Education (IE) in the Global EFA plan (2004) which mandates that both physically and intellectually disabled children should be incorporated into the public school system and should receive particular aid and support to facilitate them in their learning activities (Union of Myanmar, 2009).

In the focus group many topics were discussed. Among them was a concern that autistic individuals have access to job opportunities and are provided suitable employment. Because of recent initiatives in Myanmar, that is now beginning to materialize in society. These jobs are that of bakers, cooks, house-keeping assistants in some hotels, and other roles. To promote more effective implementation, a job coaching conference with this particular agenda was held at the Myanmar Convention Center in Yangon in September of 2014. It was sponsored by Thapyay Education Foundation, Myanmar Autism Association (MAA), Shwe Min Thar Foundation, the School for the blind in Yangon, and Pyin Oo Lwin. Creating job opportunities for people with disabilities and developing a job coaching program were actively discussed at this conference. All mothers in this study called for the development of laws and acts that protect autistic individuals and other intellectually disabled children from punishment for petty-crimes that they commit without any premeditation. The majority of participants also requested the establishment of organizations or associations which could provide comprehensive care such as boarding houses that cater to the needs of autistic individuals.

To summarize, the findings of this study show that the life experiences of mothers with autistic children are unique in the burdens that they deal with from day to day, but then so are the positive dimensions of indefatigable, life-long devotion, and unwavering love for their autistic children. Therefore, holistic, sensitive and humanistic care and support are absolutely essential for mothers of autistic children as well as for the children themselves.

Recommendations

Recommendations for parents

If a mother is informed that her child is autistic or has another learning disability, she should not relinquish hope and is obligated through love and necessity to provide appropriate training and education and support him or her as much as possible. Mothers should consult health care providers, social organizations, and support groups to enhance the life and wellbeing of the child. Mothers caring for autistic children should avoid social withdrawal and isolation by using effective coping methods and by participating in social activities as much as possible to reduce the stress resulting from raising an autistic child. A mother who has an autistic child should participate in peer group discussions, share experiences and feelings in self-help groups, and seek help from social associations to achieve the maximum quality of life for the child.

Recommendations for family members of autism and the public

Positive attitudes toward children with intellectual disabilities by family members and the public are essential for creating a supportive environment for these children. Having a relative who has autism or another learning disability should not be perceived as a shameful experience for family members. And most importantly family members should avoid blaming the child, bullying him or her, and mocking the child, let alone using violence against one who should be treated with compassion and understanding. Family members can do their part in reducing the stress experienced by mothers of autistic children by supporting them and providing care for their children.

The Public should not abnegate its responsibility in improving the lives of these children by seeing that they do not suffer from isolation, discrimination, bullying, harassment, and exploitation in the labor force. Moreover, the public should initiate foundations and organizations to promote the wellbeing of these children. The public should also promote awareness of autism as much as possible in order to obtain financial support through local donations and to assist organizations such as UNICEF and WHO at a grassroots level. The public can play a vital role in supporting and helping families.

Recommendations for health care providers including nurses

Nurses can play an essential role in caring for disabled children and providing support for the families of autistic individuals. Nurses should do the following:

i. Perform screening activities for those who might have intellectual disabilities and implement school health services.
ii. Make early notification to parents as well as provide early and appropriate referrals.
iii. Participate actively in awareness programs and advocate assimilation in public education programs.
iv. Educate mothers, especially those with children under five years old, to be alert to delayed development and unusual behaviors.
v. Advocate for both children with intellectual disabilities and their families.
vi. Collaborate and cooperate with multi-disciplinary teams including medical doctors, psychologists, speech therapists, occupational therapists, physical therapists, and social workers.
vii. Refer family members to social support groups or associations.
viii. Become involved in social organizations for people with intellectual disabilities and negotiate services provided by NGOs and INGOs.

Finally, nurses should conduct evidence-based research regarding intellectual disabilities, including autistic disorders, to promote greater understanding and further advancement in providing care and support.

Recommendations for concerned authorities

The standard diagnostic criteria for classification of intellectual disabilities should ensure early diagnosis. Formulation of effective inclusive education for all children should be a community mandate. Services for children with intellectual disabilities need to be available, accessible, and affordable. Children with intellectual disabilities should be afforded the protection of enhanced laws and legal protections that will save them from being exploited. Vocational training centers need to be established in addition to specialized schools for disabled children. For autistic individuals with high functioning intellectual disabilities there should be ample opportunities to obtain jobs as manual laborers working for the government. The teaching methodology for autistic children must be updated. There should also be refresher courses for health care providers and staff from social welfare departments who work with these children extensively. Allocating adequate staff to schools for disabled children should also be a paramount consideration for better and broader implementation of school activities and for the optimal coverage of the numbers of students. As the highest priority, the number of schools for disabled children should be expanded in almost all regions and states.

Conclusion

The care that must be given to autistic children and their families is unique and should be customized to their individual experiences and feelings. As shown in this study, autism affects maternal lives significantly, so a deeper understanding of their realities becomes ever more imperative for better supportive services such as nursing services and comprehensive care.

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